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Washington Group on Disability Statistics

Note by the Secretary-General

Summary

In accordance with a request of the Statistical Commission at its fortieth session (see E/2009/24), the Secretary-General has the honour to transmit to the Commission the report of the Washington Group on Disability Statistics. The report presents the work completed by the Washington Group and its workplan for the year 2010. The Commission may wish to note the findings and conclusions of the Washington Group and the proposal for its future work. The report is submitted to the Statistical Commission for information.

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Report of the Washington Group on Disability Statistics

I. Introduction

1. In June 2001, the United Nations International Seminar on the Measurement of Disability recommended that principles and standard forms for indicators of disability be developed for use in censuses. There was a broad consensus on the need for population-based measures of disability for country use and for international comparisons. This work was greatly needed because data on disability, especially in developing countries, are scarce and often of poor quality. Furthermore, international comparability is often lacking, even among developed countries. As a result, the Washington Group on Disability Statistics was formed to address the urgent need.

2. The main purpose of the Washington Group is, therefore, the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability that is comparable throughout the world. More specifically, the Washington Group aims to guide the development of a short set of disability measures, suitable for use in censuses, sample-based national surveys or other statistical formats for the primary purpose of informing policy on equalization of opportunities. A second priority is to recommend one or more extended sets of survey items to measure disability, or guidelines for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items are intended to be related to the short set of disability measures. The World Health Organization (WHO) International Classification of Functioning, Disability, and Health has been accepted as the basic framework for the development of the sets. All disability measures recommended by the group, short or extended, will be accompanied by descriptions of their technical properties, and methodological guidance will be given on their implementation and their applicability to all population subgroups. The Washington Group disseminates its work products globally through the World Wide Web (http://www.cdc.gov/nchs/citygroup.htm) and scientific publications.

II. Progress report on work completed

A. Meetings and collaborations

3. The Washington Group has held nine annual meetings since the inception of the group: (a) from 18 to 20 February 2002, in Washington, D.C.; (b) on 9 and 10 January 2003, in Ottawa, Canada; (c) on 19 and 20 February 2004, in Brussels; (d) from 29 September to 1 October 2004, in Bangkok; (e) from 21 to 23 September 2005, in Rio de Janeiro; (f) from 10 to 13 October 2006, in Kampala; (g) from 19 to 21 September 2007, in Dublin; (h) from 29 to 31 October 2008 in Manila; and (i) from 7 to 9 October 2009, in Dar es Salaam. Annual meetings are rotated through major geographic regions to facilitate participation, especially of the developing countries. In addition, two regional workshops were held in 2005 to provide technical assistance and training for pre-testing the proposed short set census questions.

4. The Washington Group has sought to foster international collaboration, and in particular, to ensure that the efforts of the group are broad-based and inclusive of voices from developing countries from every region of the world. Thus, representatives of national statistical authorities of organizations representing persons with disabilities and of other international organizations participate in the Washington Group. Since its inception, representatives of national statistical offices in 116 countries have participated in the Washington Group. Representatives from 82 countries have attended at least one annual meeting, and 54 countries have attended more than one annual meeting. Current members of the Washington Group include 109 national statistical offices, 7 international organizations, 6 organizations that represent persons with disabilities, the United Nations Statistics Division and other United Nations affiliates (see the annex to the present report).

5. The Washington Group continues to collaborate with the Economic Commission for Europe (ECE), WHO, and Eurostat on the Budapest Initiative (Task Force on the Measurement of Health Status). At a meeting held in Geneva in June 2009, the collaborative efforts of the Washington Group and the Budapest Initiative in developing extended sets of questions for use as components of population surveys, as supplements to surveys or as the core of a disability survey were presented. The testing of these questions has been supported by the Economic and Social Commission for Asia and the Pacific (ESCAP) as follows.

6. ESCAP has provided the funding for the cognitive and field testing of the extended set of questions developed by the Washington Group/Budapest Initiative collaboration. Initial training in cognitive and field testing procedures took place in Bangkok during February 2009, and included six ESCAP countries (Maldives, Sri Lanka, the Philippines, Mongolia, Cambodia and Kazakhstan). Those countries then participated in the cognitive and field testing of the extended question set. Canada, the United States of America and South Africa also provided cognitive interviews.

7. At the ninth meeting of the Washington Group, projects similar to those supported by ESCAP in Asia and the Pacific region were requested in other regions, particularly by delegates from African countries.

B. Recent activities and major achievements

8. Since 2001, the group has (a) developed a short question set intended for use on national censuses, accompanying rationale, and test implementation protocols; (b) provided training to countries in conducting the Washington Group tests and, more generally, on disability data collection methods; (c) conducted standardized Washington Group tests for the short set of questions in 15 countries; (d) analysed test results; (e) endorsed the short question set (with minor revisions); (f) begun development of extended question sets to be used as components of population surveys, as supplements to surveys, or as the core of a disability survey; (g) in collaboration with ESCAP, conducted standardized cognitive testing of the extended question sets in nine countries (Cambodia, Canada, Kazakhstan, Maldives, Mongolia, the Philippines, South Africa, Sri Lanka and the United States); (h) in collaboration with ESCAP, conducted standardized field testing of the extended question sets in six countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka); and (i) begun analysis of the cognitive and field test results.

Regional workshops

9. The Washington Group organized and held two regional workshops in 2005 in Africa and Latin America. These workshops were primarily directed towards countries in the region that were interested in including disability questions in their national censuses. The workshops familiarized countries in the region with the short set of Washington Group questions on disability, the accompanying rationale and the procedures for testing the questions. These workshops helped to build capacity for data collection on disability in many developing countries. In addition to receiving training for conducting the tests of the Washington Group questions, these countries are working internally to improve their overall approaches to data collection on disability.

10. The Washington Group has participated in the following regional workshops:

(a) The ECE Workshop on disability statistics in member countries of the Special Programme for Economies of Central Asia (SPECA) (Bishkek, 13-15 December 2006). The aim of the training workshop was to introduce participants to the best practices on disability statistics and to develop the know-how in methodologies of measurement of the health status of the population. It was organized for health statistics directors and staff engaged in the measurement of disabilities in the national statistical offices and ministries of health in Central Asia and Azerbaijan;

(b) Joint ECE-United Nations Population Fund (UNFPA) training workshop on census management in South-East Europe (Sarajevo, 18-22 February 2008);

(c) Workshop on strengthening capacity for disability measurement across South Asia, sponsored by the World Bank, and a regional workshop on promoting disability data collection through the 2010 Population and Housing Censuses, sponsored by the United Nations in Bangkok (April, 2008);

(d) Joint ECE-UNFPA regional training workshop on population and housing censuses for South-Eastern European countries, held in Ohrid, Macedonia (November, 2008). The workshop was organized for senior professionals and experts from the national statistical offices of Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Kosovo, Macedonia, Montenegro, Romania and Serbia. The Washington Group was responsible for a full-day training session including the measurement of disability in censuses and interpreting and understanding disability as measured using the Washington Group short set of questions;

(e) In August and September 2009, at the request of the World Bank, the Washington Group assisted the Bangladesh Bureau of Statistics through a training workshop designed to provide an understanding of disability and functioning using the Washington Group approach on International Classification of Functioning, Disability and Health (ICF); and implementing the Washington Group short set of questions in their national Household Income and Expenditure Survey and in preparation for the 2010 census.

Cognitive and field testing

11. Short set (for use on censuses): protocols for implementing tests of the short set of questions were developed by the Washington Group and standardized testing was undertaken in 15 countries, including 13 that were funded through a grant from

the World Bank. The purpose of testing was to ensure the validity of the questions and to better understand how they operate in different settings and cultures. These tests, as well as studies in other countries employing the Washington Group approach, show an improvement over traditional census questions. Developing countries that had previously reported disability rates of about 1 or 2 per cent found rates between 8 and 15 per cent when using the Washington Group questions. These rates are much more in line with data from developed countries that use more complex approaches to disability data collection.

12. Extended set: work on extended sets of disability questions intended as components of population surveys, as supplements to surveys, or as the core of a disability survey began with the development of a matrix designed to guide the development of these question sets. The matrix was presented during the eighth meeting of the Washington Group in Manila, and work progressed as follows: (a) the establishment of an extended set(s) of questions by working group; (b) the review of existing question sets already in use in other surveys (national or research); (c) a joint Budapest Initiative/Washington Group meeting held in Washington, D.C., in July 2008, to discuss further extended question set development; (d) the development of a cognitive test protocol; (e) ESCAP/Washington Group training, held from 16 to 20 February 2009, in Bangkok, to train six ESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka) in cognitive and field test procedures and the subsequent cognitive testing in these countries and in Canada, the United States and South Africa; (f) Washington Group Extended Set Analysis Workshop, held in Washington, D.C., in May 2009; (g) the development of a field test protocol and field testing in the same six ESCAP countries; and (h) the presentation of results from cognitive testing and preliminary field test results to the ninth meeting of the Washington Group in Dar es Salaam.

Provision of technical assistance

13. In addition to funding countries to conduct the tests, the Washington Group used a World Bank grant to employ a consultant from January to June 2006 to provide technical training and to support national statistics offices engaged in test activities. In-person technical support was provided to two African national statistical offices. Assistance via phone and e-mail was provided to countries in Africa and South America and to Viet Nam, the Philippines and India.

Fostering international cooperation

14. The Washington Group has worked with the Statistics Division, WHO, ESCAP, ESCWA, ECE, the International Labour Organization, the Organization for Economic Cooperation and Development (OECD), the Inter-American Development Bank, the World Bank, Eurostat, the Budapest Initiative, the Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (SINTEF) and other entities to promote a unified approach to disability measurement. Several World Bank data instruments have been heavily influenced by the work of the Washington Group (in India and Uzbekistan), and SINTEF has been working in Africa to conduct independent tests of the Washington Group questions. In addition, ESCAP and WHO, in partnership with the Australian Bureau of Statistics, conducted pilot studies on the Washington Group short set of questions and the longer WHO set of questions. The study results were presented and

discussed during the fifth and sixth Washington Group meetings. The Washington Group has also been informed that the question set has been pre-tested or added to surveys in at least 11 countries. The Washington Group has embarked upon a collaboration with ESCAP for the cognitive and field testing of the extended set of questions in six participating ESCAP countries. The Washington Group continues to dialogue with the World Bank in matters of common interest and in attempts to secure funding for further activities in the testing and development of extended sets of questions on disability in other regions.

Endorsement of a set of census questions on disability

15. At the sixth annual meeting of the Washington Group, held in Kampala, test results were reported and the short set of questions on disability was endorsed by the 23 countries and 5 international agencies in attendance. Some minor wording modifications were suggested based on pre-test results presented at the meeting. The set comprises questions on six core functional domains: seeing, hearing, walking, cognition, self care and communication. In countries where resources do not permit the inclusion of six questions on a census, the first four domains are recommended for inclusion (seeing, hearing, walking and cognition); the Washington Group, however, strongly endorses the use of the six questions. These questions were based on the model of disability inherent in the World Health Organization International Classification of Functioning, Disability, and Health with a particular emphasis on international comparability. On the basis of information obtained from the country reports submitted by the primary country representatives just prior to the ninth meeting of the Washington Group, 21 countries indicated that the short set of questions would be included in the upcoming census round. For countries indicating that the short set of disability questions would not be used in the upcoming census round, the reasons for not using the questions included:

(a) Washington Group questions were not finalized when census questions were decided;

(b) Requirement to use the same questions that were used in previous census rounds;

(c) It was too expensive to add additional questions to census;

(d) There are too many questions; the number of disability questions allowed on the census is restricted;

(e) Respondents had trouble understanding questions during pre-testing;

(f) Concerns regarding the Washington Group short set answer categories.

III. Workplan for 2010

16. At the ninth meeting, the Washington Group agreed to its workplan for 2010. Among other items, the plan delegates specific responsibilities to working groups that meet throughout the year via e-mail and telephone conferences. Next steps for the working groups include:

(a) Work on the extended sets of questions for surveys:

(i) Continued analysis of the field test results through the first half of 2010;

(ii) Expansion of cognitive and field testing of the extended set of questions to other regions, in particular, to Europe;

(b) Work on methodological issues:

(i) Assessing the applicability of the short set of questions for specific subpopulations such as children; determining the age at which the questions are meaningful by evaluating the test data from children; and developing specific question modules for children;

(ii) Designing extended set questions for the measurement of environmental factors including both barriers and facilitators;

(iii) Evaluating the proxy data.

17. It was strongly recommended by the delegates, particularly those from African countries, that projects similar to the one funded by ESCAP in the Asia and the Pacific region also be established in other regions. It was further urged that funding assistance be provided by the Statistics Division, other regional commissions, other United Nations agencies, or regional development banks to meet this request.

18. The tenth meeting of the Washington Group will be held in November 2010 in Luxembourg. Objectives for this meeting are to:

(a) Present additional work on the extended set:

(i) Results of data analyses from the completed field testing;

(ii) Update on expansion of cognitive and field testing of the extended set of questions to other regions and presentation of results (if any);

(iii) Update on any revisions to extended set questions;

(b) Present status reports from the work groups on measurement of child disability and environmental factors and the use of proxy respondents;

(c) Discuss strategic issues.

Annex

Membership of the Washington Group on Disability Statistics

1. At present the national statistical authorities sending representatives to participate in the Washington Group include those of 116 countries and areas: Albania, Argentina, Armenia, Aruba, Australia, Austria, Bangladesh, Barbados, Belgium, Bermuda, Bolivia (Plurinational State of), Botswana, Brazil, Bulgaria, Burundi, Cambodia, Canada, Chile, China, Hong Kong Special Administrative Region of China, Macao Special Administrative Region of China, Colombia, Côte d'Ivoire, Cuba, Curacao, Cyprus, Czech Republic, Democratic Republic of the Congo, Denmark, the Dominican Republic, Egypt, Estonia, Fiji, Finland, France, Gambia, Ghana, Greece, Guatemala, Hungary, India, Indonesia, Iran (Islamic Republic of), Iraq, Ireland, Israel, Italy, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Kuwait, Kyrgyz Republic, Lao People's Democratic Republic, Latvia, Lebanon, Lesotho, Lithuania, Luxembourg, Malawi, Maldives, Malta, Mauritius, Mexico, Micronesia (Federated States of), Mongolia, Mozambique, the Netherlands, New Zealand, Norway, Oman, Pakistan, Occupied Palestinian Territory, Panama, Paraguay, Peru, the Philippines, Poland, Portugal, Qatar, Romania, Rwanda, Saint Lucia, Serbia and Montenegro, Sierra Leone, Singapore, the Slovak Republic, Slovenia, South Africa, Spain, Sri Lanka, Sweden, Syrian Arab Republic, Thailand, Tonga, Trinidad, Turkey, Tuvalu, Uganda, United Arab Emirates, United Kingdom of Great Britain and Northern Ireland, United Republic of Tanzania, the United States of America, Uruguay, Venezuela (Bolivarian Republic of), Viet Nam, Zambia and Zimbabwe. In the past, the Bahamas, Comoros, Costa Rica, Ecuador, Nigeria, Tunisia, and the Turks and Caicos Islands also participated.

2. Past and present representatives of international organizations representing persons with disabilities include the European Disability Forum, Rehabilitation International, the Inter-American Institute on Disability, the African Rehabilitation Institute, and the International Federation for Spina Bifida and Hydrocephalus. Past and present representatives of national organizations representing persons with disabilities include the National Disability Authority in Ireland, the Coordination Office for the Integration of Displaced Persons (CORDE) in Brazil, the National Secretariat for Social Integration of the Disabled (SENADIS) in Panama, the Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania, the Association for Persons with Cerebral Palsy in Mexico, the Puerto Rico Council on Developmental Disabilities, the Office of the Ombudsman for People with Disabilities in Puerto Rico, the National Institute on Disability and Rehabilitation Research in the United States of America, and the National Union of Disabilities Persons of Uganda (NUDIPU).

3. Other international organizations that have previously or currently participate in the Washington Group include Eurostat, Partnership Health of the European Union, the International Labour Organization, the Organization for Economic Cooperation and Development, the Inter-American Development Bank, the International Development Project, the World Bank, the World Health Organization, the World Health Organization Family of International Classifications Collaborating Centre, the Economic and Social Commission for Asia and the Pacific, the Economic and Social Commission for Western Asia, the Economic Commission for Europe, and the United Nations Statistics Division.